‘So that at the end, you have a gentle landing’: Exploring the role and ethical dimensions of palliative care during humanitarian response to natural disasters

Takhliq Amir1, Rachel Yantzi2, Sonya de Laat3, Matthew Hunt4, Elaysée Nouvet5, Lynda Redwood-Campbell6, Laurie Elt7, Kevin Bezanson8, Carrie Bernard9

Corinne Schuster-Wallace10, Dave Wahoush1, Lisa Schwartz11

McMaster University1, McGill University2, Western University3, Lakehead & Laurentian Universities, Thunder Bay Regional Health Sciences Centre4, University of Toronto5, University of Saskatchewan6

Follow us: www.humanitarianhealthethics.net
Contact us: yantzi@mcmaster.ca, delaat@mcmaster.ca; schwar@mcmaster.ca; matthew.hunt@mcgill.ca
Twitter: @HumEthNet

— Background —

The overriding imperative of saving lives in humanitarian healthcare has often left limited room for addressing suffering and dignity, especially for individuals who are dying.

The following case study, which is focused on natural disasters, is part especially for individuals who are dying.

— Methods —

• In-depth, open-ended interviews with 11 international humanitarian aid workers and 6 local health care providers.
• Participants responded to a variety of disasters including earthquakes (Haiti, Nepal, Ecuador), typhoons/hurricanes (Philippines, India), flooding (Pakistan), and famine (Chad).
• Analysis conducted using NVivo qualitative data management software.
• Constant comparative, thematic analysis done concurrently with data collection.
• Prioritization of Palliative Care at Various Phases of the Disaster
  • Possibilities for palliative care are strongly influenced by the phase of the disaster, with more limited capacity in the initial days.
  • Many health care providers reported moral distress when they felt required to prioritize efficiency over providing comfort and symptom relief.
• Preparation for palliative care is often overlooked in the chaos of disaster response.

— Findings —

Realities of Palliative Care During Natural Disasters

Space & Privacy
• Infrastructure damage often results in a lack of space in health facilities that complicates attempts to provide palliative care.
• There is a need for space and privacy for dying patients and bereaved families.

Prioritization of Palliative Care at Various Phases of the Disaster

“...we were sitting on a bed in a crowded emergency tent, hours with all kinds of noises outside and people coming in and out and there’s just no space. That’s what we have to deal with so you had to create a little bubble the best you can.”

- International psychosocial worker

The Wounded Healer
• Local HCWs are burdened in the disaster event in a way that international responders are not.
• Local HCWs often continue to provide care while coping with the trauma of the disaster, possibly including the loss of loved ones.
• The inability to relieve the suffering of dying patients contributes to the trauma experience of disaster responders.

“...I’ve known a friend of a colleague who lost his wife, his children, his practice in the disaster, with more limited capacity in the initial days. …Many health care providers reported moral distress when they felt required to prioritize efficiency over providing comfort and symptom relief.”

- Local physician

“The you feel like in the initial phase everyone's focus was mostly on acute medical response and rescue, right? And later was long-term management and palliative care. So in my experience there were different approaches you know...so initially I think the focus for everyone was rescue, treat, rescue, treat.”

- Local physician

“...You know like I feel like in the initial phase everyone's focus was mostly on acute medical response and rescue, right? And later was long-term management and palliative care. So in my experience there were different approaches you know...so initially I think the focus for everyone was rescue, treat, rescue, treat.”

- Local physician

You just saw them all just melt to pieces and run and scream and everything. They just, it was so close to the surface.”

- International physician, during an after-shock in Haiti, 2010

Compliency of Triage
• Patient triage in natural disasters leads to considerable moral distress for care providers.
• Triage decisions are often based on limited clinical information and may not be final.
• Participants felt more needs to be done to support patients who are triaged out.

“I don’t think anyone on our team had really given thought to taking care of the people you black-tag. You black-tag them and put them in an area which is usually remote...quiet, dark and forget about them. And that’s not what palliative care is, is it?”

- International physician

Preparedness

• Capacity to offer comprehensive palliative care may be limited, particularly during the initial response, but small acts of compassion and innovative solutions can be incorporated to support dying patients and their families (i.e. grieving tents, community engagement to address psychosocial needs emotional support).

“...There was a mother in Haiti, her baby was dying, I sat with her for hours because she didn’t want me to leave her and that was okay. I didn’t want to.”

- International physician

“...I very much feel that this is something that if you don’t think of it beforehand, you’re really going to miss it completely. You’re going to miss the opportunities.”

- International physician

Possibilities for Palliative Care

Palliative Care as a Necessary Component of Disaster Preparedness
• Participants felt that unless plans are made prior to the disaster, patients with palliative needs will be neglected.
• Capacity to implement simple interventions exists but is often forgotten in the chaos of disaster response.

Small Acts of Compassion
• Participants emphasized the importance of remaining with and not abandoning dying patients and their families.
• Other examples included gathering community members to offer support to bereaved families, creating quiet spaces, and the importance of personal hygiene care in preserving dignity.

“...There was a mother in Haiti, her baby was dying, I sat with her for hours because she didn’t want me to leave her and that was okay. I didn’t want to.”

- International psychosocial worker

— Conclusions —

• Overall, participants felt that not enough was done to support dying patients during natural disaster response, yet relief of suffering was seen as an ethical imperative and important for the wellbeing of patients and responders.
• Individuals with palliative care needs are particularly vulnerable and are likely to be inadvertently neglected during a natural disaster response unless they are considered in disaster planning.
• Capacity to offer comprehensive palliative care may be limited, particularly during the initial response, but small acts of compassion and innovative solutions can be incorporated to support dying patients and their families (i.e. grieving tents, community engagement to address psychosocial needs emotional support).
• Psychosocial workers and local partners play an important role in helping teams navigate cultural dimensions of palliative care.
• Local health care providers are truly the “first responders” and are present during periods of highest mortality; therefore, efforts to build capacity for palliative care must include local providers.

Acknowledgements:
We would greatly like to thank those who participated in our study, “Ask When There is Nothing Left to Offer,” particularly those participants who were ill or whose family members were ill. We also want to thank our collaborators & supporters in Guinea, Jordan, Rwanda and elsewhere, our funders (ELRHA-R2HC), and to you for your reflections & feedback.